

KINTOA

Strength of Family, Courage of Warriors

November/December 2024



S.E.N.D

Our Way

*Let's unwrap the gift
of setting boundaries
this season!*

SUPPORT

EMPOWERMENT

NOURISHMENT

DISCOVERY

Editor's Letter

Dear Reader

As the year draws to a close, we find ourselves in a season that encourages both celebration and reflection. For many of us, December brings a complex mix of emotions—a longing for rest, a need for connection, and, sometimes, the weight of unmet expectations. The holiday season can be beautiful, but let's be honest, it can also be exhausting.

This year, let's create our own kind of holiday—a time that truly serves us and our families. Maybe that means reimagining traditions, finding comfort in quiet moments, or discovering new ways to connect without the pressure of perfection. This edition is packed with ideas to help us make the most of the season on our own terms. From crafting a cozy corner just for you to capturing small moments of joy, let's embrace what makes us feel whole.

We've also focused on reclaiming our voices, drawing strength from quiet resilience, and finding power in our own stories. Because as parent carers, our lives often go beyond what others can see, and our hidden talents, silent strength, and warrior spirit deserve to be celebrated.

Here's to a winter season that warms our hearts, fuels our spirits, and reminds us that we're not alone. Let's end the year as we started it—together, holding each other up through the challenges and finding joy in the journey.

**WARM
REGARDS,**

*Debs
Aspland*



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A Different Kind of Christmas

(Or How to Navigate December Without Losing Your Mind)



Let's talk about Christmas. Not the glossy magazine version with perfectly decorated trees and children angelically opening presents. The real version. The parent carer version. The version where success might mean getting through the day without a meltdown (yours or theirs).

The Permission Slip (Pin This to Your Fridge)

You officially have permission to:

- Skip the Christmas events that don't work for your family
- Say no to well-meaning relatives
- Create your own traditions
- Serve beans on toast for Christmas dinner
- Hide in the bathroom when needed
- Open presents over several days
- Do whatever works for YOUR family

The Reality Check (Because Someone Needs to Say It)

Christmas doesn't need to be:

- On December 25th (shocking, I know)
- Full of surprises (who actually likes those?)
- About visiting everyone
- Perfect for Instagram
- Exhausting for everyone
- Traditional anything
- What others expect

Christmas can be:

When it works for you
Calm and quiet
At your own pace
In your own way
Different every year
Simple and small
Actually enjoyable

The Window Tree Revolution (Or How Getting Creative Saved Christmas)

Let me tell you a story about Christmas trees. For years, we couldn't have one. The sensory overload of lights, the temptation of baubles, the space it took up - it just didn't work for our family. Pinterest-worthy living rooms seemed like a distant dream, and I'll admit, I felt a bit sad about it.

Then we discovered window trees.

Armed with window markers (and questionable artistic skills), we started drawing our Christmas tree on the window instead. No baubles to break, no pine needles to Hoover, no lights to untangle - just festive creativity that could be wiped away when needed.

The funny thing? Even now we have a real tree, we still draw our window tree. It's become our tradition. Our thing. Our way of saying "we did Christmas our way, and it worked."

REAL CHRISTMAS JOY ISN'T ABOUT PERFECT DECORATIONS, ELABORATE MEALS, LOTS OF PRESENTS, FAMILY GATHERINGS, SOCIAL EVENTS, TRADITIONAL ANYTHING. IT'S ABOUT FINDING PEACE, CREATING CALM, MAKING MEMORIES, BEING TOGETHER, FEELING SAFE, FINDING JOY, SURVIVING WELL.

A different kind of Christmas

... Continued

The Great Present Revolution (Because Who Made Wrapping Paper Mandatory?)

Here's another truth bomb: there is absolutely NO LAW that says Christmas presents must be wrapped.

I repeat: NO LAW.

Not a single piece of legislation exists that demands you spend hours wrestling with sellotape and paper that will be destroyed in seconds. Instead, try:

- Presents in plain sight (immediate gratification!)
- Gift bags (reusable and easy)
- Pillow cases (perfect for sensory-sensitive unwrapping)
- Treasure hunts (if your child enjoys them)
- Special boxes (that can be used year after year)
- Under a blanket (simple but effective)
- In a special Christmas sack (minimal wrapping required)

The Survival Strategies (Tested by Real Warriors)

Managing Expectations (Others' and Your Own)

Tell people early:

- What you can and can't do
- How long you can stay
- What your child needs
- What helps and what doesn't
- Why surprises don't work
- What makes visits successful
- When you need to leave



Christmas doesn't need to be on December 25th, full of surprises, about visiting everyone, perfect for Instagram, exhausting for everyone, traditional anything, what others expect.

The Sensory Survival Kit (For when it all gets too much):

- Quiet spaces identified
- Escape routes planned
- Familiar items packed
- Comfort objects ready
- Safe foods available
- Noise cancelling options
- Calm down kit prepared

The Family Navigation Guide (For Those "But It's Christmas!" Conversations)

Helpful phrases:

- "We're doing what works for our family this year"
- "We'll join you when/if we can"
- "That's not going to work for us, but here's what might..."
- "We need to put our child's needs first"
- "A shorter visit will be better for everyone"
- "We'll celebrate with you another day"
- "Thank you for understanding"

CHRISTMAS MAGIC ISN'T FOUND IN THE PERFECT DECORATIONS. IT'S FOUND IN THE MOMENTS THAT WORK FOR YOUR FAMILY. EVEN IF THOSE MOMENTS INVOLVE WINDOW PENS AND UNWRAPPED PRESENTS.

A different kind of Christmas

... Continued

More "Rules" You Can Break (Because Who's Checking?)

You don't need to:

- Wait until Christmas morning
- Open all presents at once
- Have surprise presents
- Use glittery cards
- Sing carols
- Wear scratchy Christmas jumpers
- Eat turkey
- Watch the King's speech
- Play charades
- Have crackers that bang
- Do anything that doesn't work for your family

The Alternative Decorations Guide (Beyond the Traditional Tree)

Try:

- Window drawings (our personal favourite!)
- Paper chains (easy to replace if needed)
- Removable wall stickers
- Ribbon trees on walls
- Lego decorations
- Soft decorations only
- Pictures of decorations
- Whatever works for you

The Practical Bits (Because Theory is Nice but Reality Helps)

Before the Day:

- Prepare your child with visual schedules
- Set up calm spaces
- Plan escape routes
- Stock up on safe foods
- Keep decorations manageable
- Have backup plans
- Lower expectations (then lower them again)



On the Day:

- Take it slow
- Follow your child's lead
- Keep to usual routines where possible
- Have quiet times planned
- Keep food simple
- Accept help
- Breathe

After the Day:

- Recovery time is essential
- Return to routine gradually
- Process at your own pace
- Celebrate what worked
- Note what didn't
- Plan for next time
- Be kind to yourself

Remember:

Christmas magic isn't found in the perfect decorations.

It's found in the moments that work for your family.

Even if those moments involve window pens and unwrapped presents.



SEND Parent Carer Quiz

Bringing something a little bit different in this edition, not our usual quiz type.

Perfect for holiday gatherings, support group parties, or just a bit of fun with fellow parent carers. Keep track of your scores and remember - we're all learning together!

How to Play

- Split into teams or play individually
- Arrange a "group video chat" with a drink with fellow parent carers.
- One person can be the quiz master
- Award one point per correct answer
- No googling allowed! 😊
- Discuss answers together - sharing experiences is part of the fun

Round 1: SEND Rights & Regulations

1. In England, what age range does an Education, Health and Care Plan (EHCP) cover?

- A) 0-16 years
- B) 0-18 years
- C) 0-25 years
- D) 0-21 years

2. How many weeks does a local authority legally have to respond to an EHCP request?

- A) 20 weeks
- B) 12 weeks
- C) 16 weeks
- D) 24 weeks

JUST FOR FUN!
TAKE A GUESS - WHAT PERCENTAGE OF LOCAL AUTHORITIES DO WE THINK CONSISTENTLY MEET THE LEGAL TIMELINE? NO RIGHT OR WRONG ANSWERS HERE - IT'S ABOUT SHARING OUR JOURNEYS AND HAVING A KNOWING LAUGH TOGETHER!



3. What does SENDIASS stand for?

- A) Special Educational Needs Direct Information And Support Service
- B) Special Educational Needs and Disability Information, Advice and Support Service
- C) Special Educational Needs Dedicated Independent Advisory Support System
- D) Special Educational Needs Development, Information and Support Scheme

Round 2: SEND Terminology

4. What does 'stimming' typically refer to?

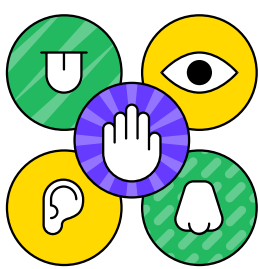
- A) Stimulus training in education
- B) Self-stimulatory behavior
- C) Stimulated learning methods
- D) Student immersion techniques

5. What is echolalia?

- A) A type of communication aid
- B) A learning style
- C) Repetition of words or phrases
- D) A sensory processing term

6. What does AAC stand for in SEND terms?

- A) Advanced Autism Communication
- B) Augmentative and Alternative Communication
- C) Adaptive Assistance Communication
- D) Additional Academic Curriculum



SEND PARENT CARER QUIZ

CONT/D.....

Round 3: Fun Facts

7. Which sense typically develops first in babies?

- A) Sight
- B) Hearing
- C) Touch
- D) Taste

8. How many different types of sensory receptors does the human body have?

- A) 5
- B) 7
- C) 10
- D) More than 10

9. What percentage of the human brain is developed by age 5?

- A) 50%
- B) 70%
- C) 90%
- D) 100%

WHAT'S THE MOST UNEXPECTED SENSORY TRIGGER YOU'VE DISCOVERED AND ADAPTED TO? SHARE YOUR CREATIVE SOLUTIONS - SOMETIMES THE MOST UNUSUAL FIXES WORK THE BEST! WHO HAS THE MOST UNIQUE SENSORY HACK?

Round 4: Practical Knowledge

10. What colour overlay is commonly used to help with reading difficulties?

- A) Blue
- B) Yellow
- C) Green
- D) All can be effective for different people

11. Which side of the brain is typically associated with language processing?

- A) Right
- B) Left
- C) Both equally
- D) It varies by person

112. What type of lighting can often be challenging for individuals with sensory sensitivities?

- A) LED
- B) Fluorescent
- C) Natural
- D) Incandescent

JUST FOR FUN!
CREATE A "TOP TIPS LIST": EVERYONE SHARE YOUR BEST PRACTICAL DISCOVERY OF THE YEAR - IT COULD BE ANYTHING FROM A BRILLIANT SCHEDULING APP TO A LIFE-CHANGING FIDGET TOY.

ANSWERS

- C) 0-25 YEARS
- A) 20 WEEKS
- B) SPECIAL EDUCATIONAL NEEDS AND DISABILITY INFORMATION, ADVICE AND SUPPORT SERVICE
- B) SELF-STIMULATORY BEHAVIOR
- C) REPETITION OF WORDS OR PHRASES
- B) AUGMENTATIVE AND ALTERNATIVE COMMUNICATION
- C) TOUCH
- D) MORE THAN 10
- C) 90%
- D) ALL CAN BE EFFECTIVE FOR DIFFERENT PEOPLE
- B) LEFT
- B) FLUORESCENT



From Overwhelmed to Organised: Discover Life AsPland

Parenting children and young adults with special educational needs and disabilities (SEND) comes with unique challenges, and as a mum of three, Debs knows this all too well. Love is the foundation, but to navigate the daily complexities, you need more, you need a solid strategy. That's where Life AsPland comes in.

Life AsPland offers a range of organisers and downloadable templates, specifically crafted to meet the needs of SEND families.

Designed for SEND Families Cut Through Chaos, Save Time Feel Empowered with Every Plan

Born from Debs' real-life experiences, Life AsPland is all about turning the chaos of SEND parenting into manageable, stress-free routines. Take charge of your family's journey—let Life AsPland guide you to a more organised and balanced life.

*Debs
Aspland*



FIND OUT MORE AT: LIFEASPLAND

Beyond the label

Because you're more than just "parent carer"

Let's play a quick game. When was the last time you answered the question "What do you do?" without using the words "I'm just a...?"



*It's what you do,
not all you are*

Go on, I'll wait.

sound of kettle boiling

sound of biscuit packet opening

sound of someone else's appointment letter arriving

Still thinking? Thought so.



The Identity Shift

Remember when you used to be:

- The one who always had a new book to recommend
- That person who could make anyone laugh
- The weekend adventurer
- The creative soul
- The music lover
- The story collector
- The dream chaser
- The cake enthusiast (okay, that one's still true)

And then suddenly you became:

- The appointment keeper
- The medication tracker
- The form filler
- The professional meeter
- The eternal waiter
- The constant advocate
- The system navigator
- The professional apologist

The Truth About Labels

Yes, you're a parent carer. But you're also:

- A detective (finding resources)
- A warrior (fighting the system)
- A diplomat (handling professionals)
- A researcher (googling at 3am)
- A juggler (literally everything)
- An advocate (obviously)
- A comedian (dark humour counts)
- A superhero (cape optional)

The Parts They Don't See

You're still:

- The one who snort-laughes at inappropriate moments
- That person who knows all the words to 80s power ballads
- The secret chocolate hide-and-seek champion
- The master of silly voices
- The kitchen dancer
- The dream holder
- The hope keeper
- The joy finder

Beyond the Label

Continued.....



The Reality Check

Being a parent carer is part of your story, not your whole story. It's a significant chapter, not the entire book. It's a role you play, not your only performance. It's what you do, not all you are.

The Identity Reclamation Project

Step 1: The Memory Lane Walk

Remember when you used to:

- Have hobbies that didn't involve form filling
- Read books that weren't medical journals
- Watch TV shows that weren't educational
- Have conversations that didn't involve appointments
- Wear clothes without worrying about sensory needs
- Make plans without checking therapy schedules
- Dream about things just for you

Step 2: The Permission Slip

Permission to:

- Have interests beyond caring
- Dream about your own future
- Take up space
- Have bad days
- Want more
- Need help
- Just be

Step 3: The Rediscovery

Try:

- Reading one non-medical book
- Listening to your old favourite songs
- Wearing something because you like it
- Having one chat not about caring
- Spending 5 minutes on an old hobby
- Dancing in the kitchen
- Dreaming a little dream

The Identity Toolkit

You are:

- A whole person (even in yesterday's clothes)
- A unique individual (beyond the caring role)
- A dream carrier (even if they're on pause)
- A story writer (of your own narrative)
- A journey taker (at your own pace)
- A joy finder (even in chaos)
- A heart holder (including your own)



The Emergency Response Kit

- When you forget who you are:
- Read old diaries
- Look at old photos
- Call an old friend
- Listen to your music
- Wear your favourite things
- Dance your dance
- Dream your dreams
- Be your you

Remember:

You're not just any one thing, you're everything you've always been, plus everything you've become, and everything you're yet to be. Even if right now you're wearing mismatched socks and yesterday's ponytail.

Micro Moments of Joy



Let's talk about joy. Not the big, life-changing moments that happen once in a blue moon. Not the Instagram-worthy achievements. The tiny ones. The ones that might seem ridiculous to celebrate, but absolutely deserve a silent fist pump or happy dance in the kitchen.

The Everyday Magic

You know those moments? When you find a pen that actually works just as you're about to write something down. When you discover your tea is still hot because nobody interrupted you for a whole five minutes. When you get through a professionals' meeting without crying (much). These aren't the kind of achievements you'll see on social media, but they're worth celebrating all the same.

I had one of those moments yesterday. I found both socks of a pair, in the same wash load, on the same day. I'm thinking of adding it to my CV under 'Special Achievements'

Sometimes the biggest celebrations are for the smallest things. Like the happy dance you do in your kitchen, alone, because you found that appointment letter you thought you'd lost.

Morning Glory

Speaking of achievements, let's talk about mornings. You know you're living your best parent carer life when success means everyone is wearing clothes (mostly theirs), most people have shoes (mostly matching), and you've managed to brush someone's hair (possibly your own). If you actually remember the PE kit on PE day, you're basically superhuman.

The other morning, I arrived at the college on time, with all the right bags, and remembered to hand in a form. I was so proud of myself until I realised I was still wearing my slippers. But hey, two out of three isn't bad.

JOY

Professional Victories

There's a special kind of joy in those tiny wins during professional meetings. Like when you not only have a pen, but it actually works. Or when you manage to say something intelligent before your brain goes foggy. Or when you successfully advocate for your child while only saying "um" forty-seven times instead of the usual hundred.

Last week, I actually remembered what was discussed in a TAC meeting AND found my notes afterwards. I'm considering having t-shirts made to commemorate the occasion.

Micro moments of Joy

Hospital Heroes

Some of the sweetest moments happen in the most unexpected places like hospitals. Finding a parking space near the entrance. The coffee machine actually working. The moment when you see your favourite nurse is on duty. The triumph of remembering to pack snacks. The victory of free WiFi that actually connects.



Nighttime Ninjas

Night-time brings its own opportunities for tiny celebrations. Successfully finding medication in the dark without turning on the lights (and waking everyone up). Remembering which child needs what without having to check your notes. Getting back to sleep after being up for the third time. Your phone actually having battery left when you need it at 3am.

Unexpected Treasures

Sometimes joy sneaks up on you. It's in finding chocolate you forgot you hid. It's your favourite mug being clean exactly when you need it. It's the phone ringing and it actually being a friend rather than another professional. It's having enough milk for one more cup of tea.

The Expert Evolution

There's a special kind of satisfaction in realising how far you've come. Like when you understand the medical jargon without Google's help. When you can spell your child's condition without checking. When you know so many acronyms you could probably write a dictionary.

Finding Your Moments

Joy doesn't have to be Instagram-worthy. It doesn't need to be perfect or planned or impressive. It can be tiny and private and ordinary. It can be as simple as drinking a warm cup of tea, finding both shoes, or having a moment of quiet.

Sometimes the biggest celebrations are for the smallest things. Like the happy dance you do in your kitchen, alone, because you found that appointment letter you thought you'd lost. Or the quiet fist pump when you make it through another day.

And yes, I still celebrate finding matching socks. Every single time.

Because in this parent carer life, sometimes the smallest wins are actually the biggest victories. And if you want to do a victory dance because you remembered to post that form, or high-five yourself because you managed to drink your tea while it was still hot go for it.

You might look ridiculous. But that's okay.

Those are exactly the kind of moments worth celebrating.

RECLAIMING YOUR VOICE

Remember when you used to apologise for speaking in meetings? When you'd start every sentence with "I'm not sure, but..." or "I might be wrong..."? When you'd feel your heart racing before questioning a professional's opinion?

Let's talk about that journey from "Sorry to bother you, but..." to "Actually, I need to point something out."

The Evolution of Your Voice

(A Field Guide to Parent Carer Communication)

Stage 1: The Early Days

- Nodding politely while understanding nothing
- Googling words after meetings
- Writing questions but never asking them
- Thinking everyone else knows better
- Apologising for existing

Stage 2: The Awakening

- Realising you've read more research than most GPs
- Understanding that "professional opinion" isn't always right
- Discovering you can spell conditions most people can't pronounce
- Starting to trust your gut
- Only apologising every other sentence

Stage 3: The Warrior Emerges

- Speaking without starting with "sorry"
- Making eye contact without flinching
- Challenging without apologising
- Taking your space at the table
- Knowing your worth



Finding Your Voice

(Even When It's Hiding Under Paperwork)

The Meeting Toolkit

- Prepare your points (and your snacks)
- Take notes (or pretend to while gathering thoughts)
- Ask questions (even the "silly" ones)
- Challenge politely (it's allowed)
- Remember you're the expert in your child

The Power Phrases

Instead of: "Sorry, but I think..."

Try: "I've noticed that..."

Instead of: "I might be wrong, but..."

Try: "In my experience..."

Instead of: "I don't really understand..."

Try: "Could you explain that differently?"

Instead of: "I'm may just be the parent..."

Try: "As the person who knows my child best..."

You are the expert in your child, the constant in their care, the voice of their experience, the keeper of their history, the champion of their needs, the one who's there at 3am, the coordinator of their care, the researcher of their condition, the manager of their wellbeing, the advocate they need.

RECLAIMING YOUR VOICE

Continued.....



The Art of Being Heard

What You Bring to the Table:

- 24/7 experience with your child
- Detailed knowledge of their needs
- Understanding of what works
- Insight into their challenges
- Expertise in their daily life
- The ability to spell their condition without checking
- A sixth sense about their wellbeing
- More research hours than a PhD student

Your Rights at Any Meeting:

- To ask questions
- To challenge decisions
- To request clarification
- To disagree
- To need time to think
- To change your mind
- To say no
- To bring cake (always valid)

You are not:

- Just a parent
- Too emotional
- Making a fuss
- Being difficult
- Overreacting
- Too demanding
- Ask too many questions
- Taking up too much time



The Truth About Voice

It's okay if:

- Your voice shakes
- You need to pause
- You have to read from notes
- You cry in meetings
- You forget your words
- You need to step out
- You change your mind
- You ask for help

Because having a voice isn't about:

- Being the loudest
- Never showing emotion
- Always being right
- Having perfect words
- Never needing support



It's about:

- Being heard
- Standing firm
- Keeping going
- Speaking up
- Showing up
- Not giving up

Remember:

- Your voice matters.
- Your experience counts.
- Your knowledge is valuable.
- And yes, you really do know what you're talking about.

Even if you're saying it while wearing yesterday's mascara and drinking cold tea.



Remember

In this season of giving, you deserve moments of peace too. Let go of the 'perfect' holiday and embrace small pockets of calm—your children benefit most from a parent who's present, not perfect.

And don't worry about the full make up either

The Winter Garden



Winter gardening. Not the glossy magazine version of winter gardening with perfectly pruned roses and immaculate borders. The real version. The parent carer version. The version where sometimes the only gardening you manage is rescuing the spider plant from your child's 3am "reorganisation" of their bedroom.

A Story About Hope

(And How Two Days Changed Everything)

Let me share something personal. During lockdown we did a garden makeover, like many people. And I have loved it ever since. However, this year, due to health reasons, I watched my garden slowly disappear under weeds and overgrowth. Every time I looked out of the window, I felt a mix of guilt and helplessness. Poor health meant I couldn't tackle it myself, and the more overwhelming it became, the more it affected my mental health. It was a visual reminder of all the things I couldn't manage.

Then my husband did something that changed everything; he arranged for a gardener to come for two days. Just two days. That's all it took to transform not just the garden, but my whole outlook. Suddenly, I could see past the chaos. I could look out of my window and see possibility instead of overwhelm.

I know not everyone can afford a gardener (trust me, I really do know), but this taught me something important: sometimes the biggest impact on our wellbeing comes from just being able to see and enjoy our green spaces, however we manage to create them.



November and December

The Indoor/Outdoor Shuffle

Outdoor Quick Wins

- Rake leaves (or declare them a wildlife habitat)
- Move one pot at a time closer to the house
- Fill bird feeders
- Clear just the path edges (forget the rest)

Indoor Garden Paradise

Your Indoor Garden Starter Kit:

- A sunny windowsill
- Some small pots (recycled containers work fine)
- Basic compost
- A few easy plants
- Hope, lots of hope!

Perfect Plants for Indoor Growing:

- Spider plants (nearly indestructible)
- Peace lilies (tell you when they need water by drooping)
- Pothos (grows in almost any light)
- African violets (continuous flowers)
- Cacti (forget to water? They don't mind)
- Succulent cuttings (ask friends)

Kitchen Windowsill Winners:

- Microgreens (ready in days)
- Sprouted seeds (instant gratification)
- Herbs in pots (fresh mint for tea or Pimms)
- Spring bulbs (watching them grow is therapeutic)
- Avocado pits (free entertainment)



The Winter Garden

Managing the Overwhelming Outdoor Space

(When a Gardener Isn't in the Budget)

The Bite-Size Approach:

- Pick one tiny area (doormat sized)
- Clear just that bit
- Celebrate that win
- Let that be enough

The Strategic Abandon:

- Declare wild areas "wildlife gardens"
- Create "meadow zones" (no mowing required)
- Let some areas "naturally rewild"
- Focus only on what you see from windows

Budget-Friendly Solutions:

- Use cardboard to suppress weeds
- Accept some "weeds" as features
- Share tools with neighbours
- Join local plant-swap groups
- Save seeds
- Take cuttings

The Indoor/Outdoor Balance

Indoor Days:

- Tend windowsill plants
- Start seeds
- Plan spring growing
- Watch garden birds
- Research easy plants
- Order seed catalogs (free entertainment)

Outdoor Moments:

- Five-minute fresh air breaks
- Quick path clearance
- One pot moved
- Bird feeder filled
- Single plant watered
- Handful of weeds pulled

Nature shows us such gentle wisdom: plants are forgiving of our mistakes and never judge. Indoor gardening counts just as much as any grand garden, and those small changes add up beautifully. Windows work both ways - bringing light to your plants while letting you connect with the world outside. And through it all, there's always tea to help.



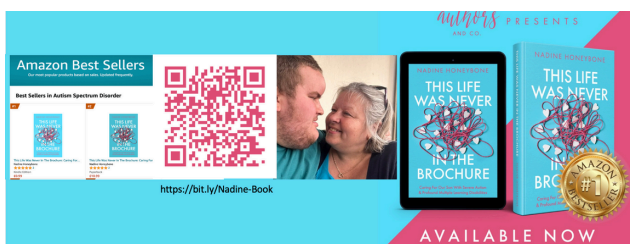
Life after my son left home



NADINE HONEYBONE
DIRECTOR
BEST SELLING AUTHOR

It's been almost 20 months since Tommy moved into his new place, and he is now looked after 24/7 by a team of carers who do everything for him. Importantly by a team of carers who get enough sleep to have the energy to attend to his needs and demands that he puts on them almost constantly.

I couldn't have wished for a better outcome for him and us. It was a hugely difficult process in finding the right place for him, getting the funding agreed, and the transition on the day from home to there when he didn't have a clue what was going on or about to happen. I think back to that day often when he jumped in the car to go out as he did every day, not knowing he would not return to his home but to a new place to live. He doesn't have the capacity to understand social stories or use picture reference systems, and I thought this would be really tough. As he has proved to us time and time again, he has the ability to accept change more than we realise.



He settled quickly there and soon became a main personality in the home. All the time he was growing up I just could not see or accept that he could be looked after any better by people other than me. Turns out he can and he is. It still was the hardest decision I have ever had to make in my life - to agree for him to move into a care home at the age of 18. Truth be told it was the best decision, both for him and for us.

*The full story from when he first had his diagnosis of autism at the age of 2, up to moving out at 18 has been told in my book **"This Life Was Never In The Brochure"**. But the story continues as we both navigate the new chapter in our lives.*

I have continued to see him on a regular basis on weekends. Firstly this started out by meeting him and his care team at local spots where we could walk or go into a cafe. Come the time to say goodbye though I struggled emotionally. Each time the feeling of making that decision came back time and time again. He got into his car, I gave him a kiss, said 'I love you lots like' and he replied 'Jelly'. His word for 'love you too'. They drove away and I was left an emotional wreck again in my car until I had the composure to drive home.

Since I have been allowed to drive him in my car, with his carers following behind, we have enjoyed just being together for an hour or so driving to local places. Sometimes getting out at a destination and sometimes not.



IT STILL WAS THE HARDEST DECISION I HAVE EVER HAD TO MAKE IN MY LIFE - TO AGREE FOR HIM TO MOVE INTO A CARE HOME AT THE AGE OF 18. TRUTH BE TOLD IT WAS THE BEST DECISION, BOTH FOR HIM AND FOR US.



Q In the way back he could tell we were nearing the end of our drive and he begins to repeat 'bus' over and over again. This is his word for wanting to go out in the car and he often gets fixated on it. We arrive back at his place and I have learnt the best thing now is to get him into the house and say a quick goodbye and let the team handle the rest. I jump back in the car, head a few meters down the road out of sight and burst into tears, every single time.

Healing from trauma

He is in the best place with the best care team around him. We are slowly healing ourselves and able to live our lives again. It really is the best outcome for us all. So why do I get so emotionally upset every time I say goodbye to him after a visit.

Trauma is a funny thing. Not laugh out loud funny, but unpredictable, deep and like grief, it doesn't go away. I read a great article on grief recently and it said that the 'size' of your grief never diminishes, but your life around it grows. I think that's the same for trauma too.

What helps for me is talking about it and being heard by friends that know I don't need their opinions on it or what I can do to fix it, but just acceptance for my story and how I am feeling. Most of the time I am in a good place and feeling grateful for all that we have, including the great result we had with Tommy's care and trusting that all will be good in the future. I know what may come may not be all good, but I have a choice now to trust and believe it will be.

We all know what it's like to worry about the future, and that most of what we worry about never comes true anyway. What a lot of wasted worry on nothing.

TRAUMA IS A FUNNY THING. NOT LAUGH OUT LOUD FUNNY, BUT UNPREDICTABLE, DEEP AND LIKE GRIEF

What if we were to be excited about the future instead, not knowing what's coming? Yes that may not come true either but we've had the feeling of excitement anyway. My mentor always says 'enjoy your future in advance just in case it doesn't happen'. Taking that concept further, the natural law of attraction makes it far more probable that you will actually get what you feel about now, in the future.

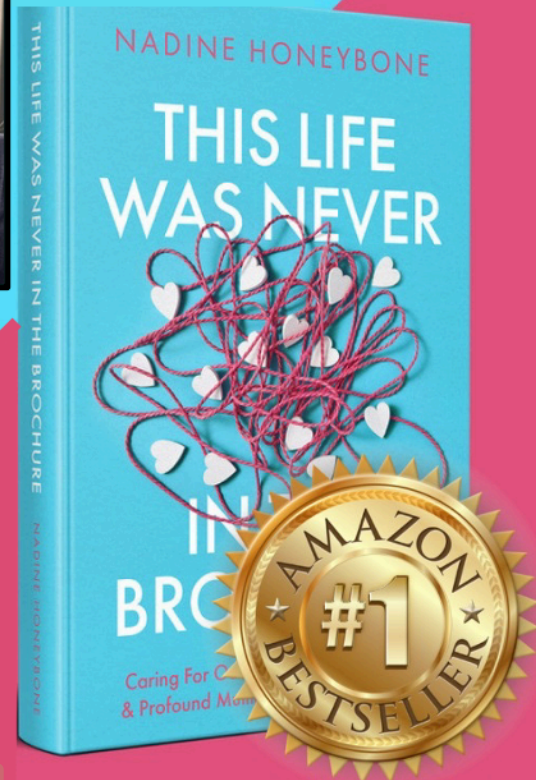
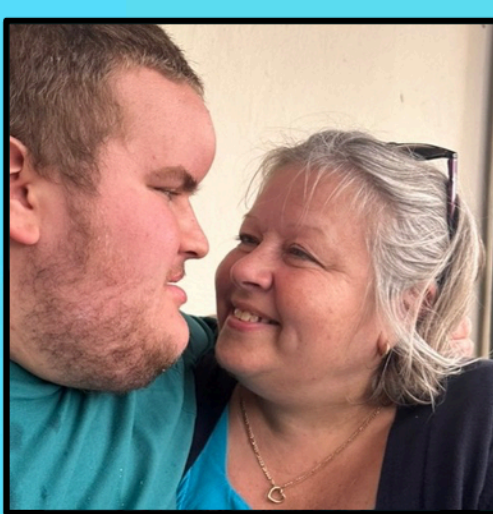
What this means to me now is that whilst I get emotionally upset each time I say goodbye to him after a visit, I know it passes and I am engulfed again in the gratitude of the situation soon after. Being happy doesn't mean never feeling sad.

I hope that anyone in the same position as we were 2 years ago, having to decide to allow their son or daughter to move out of the home and be cared for elsewhere by people you don't even know, can take some comfort in our story and how well it can turn out for everyone.

When I accepted that it just wasn't possible for us to care for him anymore, when I knew we had absolutely nothing left in our reserves to give, when facing the thought of my most precious son being cared for by strangers and when I felt I had no other choice and my heart was breaking into pieces - I surrendered to trust. And trust has been my most special friend ever since.

Nadine x



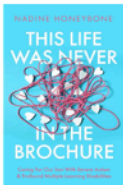


Amazon Best Sellers

Our most popular products based on sales. Updated frequently.

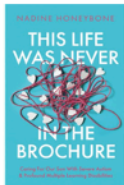
Best Sellers in Autism Spectrum Disorder

#1



This Life Was Never In The Brochure: Caring For...
Nadine Honeybone
★★★★★ 2
Kindle Edition

#2



This Life Was Never In The Brochure: Carin...
Nadine Honeybone
★★★★★ 2
Paperback



<https://bit.ly/Nadine-Book>



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What are you looking for?



THE AUTISM DIRECTORY
Est. 2010

The Warrior's Rest

Rest. And before you snort-laugh into your cold tea, I don't mean those Instagram-worthy "self-care Sunday" moments with bubble baths and face masks. I mean real rest. Parent carer rest. The kind of rest you grab between medication times, or in hospital waiting rooms, or while hiding in the kitchen pretending you can't hear the chaos in the living room.

The Midnight Thoughts

It's 3am. Again. You're awake because someone needs something, or because your brain has decided this is the perfect time to remember that form you forgot to sign, or because sleep is just being particularly elusive tonight. The house is quiet(ish), and you're sitting in the dark, wondering when rest became such a distant memory.

I had a professional once tell me to "make sure I got enough sleep." I still regret not asking her if she could pop round and explain that to my children.

The Art of the Micro-Rest

I've become something of an expert in what I like to call the micro-rest. Those tiny moments when you can just... stop. Like when you're waiting for the kettle to boil, and instead of filling those two minutes with another task, you just stand there. Breathing. Being. Existing without doing.

The other day, I found myself having a moment of perfect peace while searching for a lost shoe under the sofa. I was stuck down there anyway, so I thought I might as well enjoy the quiet. Sure, I was face-to-face with some questionable crumbs but it was oddly peaceful.



The Waiting Game

We spend so much time waiting as parent carers. Waiting in appointments. Waiting on hold. Waiting for assessments. Waiting for answers. Instead of fighting it, I've learned to claim these moments. To let my shoulders drop, just a little. To breathe, just a bit deeper. To rest, just for now.

Last week, I had to wait 40 minutes in a hospital corridor. Instead of using the time to catch up on emails or chase appointments, I just sat. I watched people walk by. I counted the ceiling tiles. I did absolutely nothing productive, and it was glorious.

The Kitchen Sanctuary

There's something about kitchens. Maybe it's because that's where the tea lives. Maybe it's because it's the one room where people sometimes leave you alone (unless they're hungry, which is always). I've learned to make it my sanctuary.

Sometimes, when it all gets too much, I just stand at the kitchen counter. I might pretend I'm doing something important with the shopping list, but really, I'm just breathing. Resting. Being.



The Warrior's Rest

Cont/d

The Night Watch

Night-time parenting is a special kind of exhausting. But there's also a strange peace in those quiet hours. When the world is sleeping (even if your child isn't), there's a gentleness to the darkness. A permission to be slow, to be quiet, to just be.

I've found my own rhythm in these hours. The familiar dance of medication and comfort, of quiet words and gentle movements. It's not rest as most people know it, but there's a restfulness in the routine.

The Hidden Spaces

We all need our hiding places. Mine is the car, after drop off, hiding in a supermarket car park. It's warm, it smells nice, and nobody looks for me.

I have a friend who takes her rest in the greenhouse. And another who swears by her daily "very important bathroom break" that mysteriously coincides with when the post arrives (and might involve chocolate).

The Gentle Truth

Rest doesn't always look like sleep (though sleep is nice when it happens). Sometimes it looks like sitting in your car for an extra minute after arriving somewhere. Like drinking your tea while it's still hot enough to taste. Like scrolling through your phone looking at pictures of dogs wearing hats.

Sometimes rest is physical actually sitting down, actually closing your eyes, actually stopping.

Sometimes it's mental, letting go of the planning, the worrying, the endless mental load, just for a moment.

Sometimes it's emotional, allowing yourself to feel what you feel without having to fix it or change it or make it better.



The Reality

We can't always get the rest we need. That's just the truth of our lives. But we can learn to find rest in the spaces between. In the quiet moments. In the pauses. In the waiting. In the being.

And yes, sometimes that means hiding in the bathroom eating chocolate. Or counting ceiling tiles in hospital corridors. Or finding peace while looking for lost shoes under the sofa.

Because rest isn't always about sleeping. Sometimes it's just about stopping. Even if it's just for a moment. Even if it's just for now. Even if it's just until someone needs their next medication. Or until someone can't find their other shoe.

Or until the kettle boils.

It still counts.



Understanding Parent Carer Trauma



A groundbreaking discussion paper released in May 2024 brings much-needed attention to an often overlooked aspect of caring for children with Special Educational Needs and Disabilities (SEND) - **the emotional impact and trauma that parent carers may experience.**

You're Not Alone

Being a parent carer can feel times. Perhaps you find yourself countless medical appointments from constantly fighting for experience heightened around a child's health or future, or constantly "on edge" or in "survival mode". Many parent carers describe feeling isolated or misunderstood by others who don't share similar experiences, and the emotional journey around diagnosis or challenging moments can feel overwhelming.

The paper emphasises a crucial message: feeling distressed or traumatised can be an understandable response to an unexpected and stressful situation. There is no need to feel guilty or ashamed for feeling this way.

Understanding Parent Carer Trauma

The research reveals that trauma for parent carers often looks different from what many people typically think of as trauma. Rather than stemming from one significant event, it can develop from ongoing challenges and repeated stressful experiences. This might include the process of receiving diagnoses, the continuous

effort to secure appropriate support and services, managing complex medical needs, navigating educational systems, and dealing with societal attitudes and misunderstandings.

Looking After Yourself

Taking care of yourself isn't selfish - it's essential. The paper encourages parent carers to find ways to connect with others who understand their journey, whether face-to-face or online. Making time for self-care, even if it's just small moments in the day, can make a significant difference. Professional support can also play a valuable role when needed. Remember, you're doing an incredibly important and challenging role, and being kind to yourself is crucial.

Hope for the Future

Despite the challenges, the research shows an encouraging truth: most parent carers do manage to live positive and fulfilling lives, even when things are difficult. While ups and downs are part of the journey, there is always hope for feeling better and finding ways to cope.

Finding Support

If you're struggling, please know that support is available. Your GP can be a good first point of contact for accessing emotional support, and several specialised organisations offer support specifically for parent carers.

The paper is available to read in full [here](#).

Final Thoughts

Recognising that you may be experiencing trauma doesn't mean you've failed - it means you're human and responding to extraordinary circumstances. Seeking support isn't a sign of weakness but a step toward better wellbeing for both you and your family. You're not alone on this journey, and reaching out for help when needed shows strength, not weakness.

Survival Food Kits:

Quick Ideas When You're Stretched Thin



Putting together a simple food kit can be a lifesaver during the intense winter months of caring. Whether you're unexpectedly staying late at the hospital or stuck on hold with yet another agency, having emergency supplies within reach can make a real difference to your day.

The Bedside Drawer Kit

Create a little sanctuary right where you need it most. A small box filled with individually wrapped items means you've got sustenance during those long night-time wake-ups. Cereal bars, dried fruit, crackers, and chocolate-covered nuts can offer both quick energy and comfort when you're too tired to venture to the kitchen.

The Hospital Bag Essential

Pack a small insulated bag with items that can withstand being forgotten at the bottom of your bag. Think ambient temperature drinks, crackers with long shelf lives, and individually wrapped biscuits. Don't forget those essential tea bags and a small jar of instant coffee - because hospital coffee isn't always what you need at 3am.

The Car Kit

Winter journeys to appointments can be unpredictable. Keep a small container in your car with:

- Bottled water
- Cereal bars or flapjacks
- Mixed nuts (if allergies aren't an issue)
- Long-life ambient snacks

The Paperwork Station

Those marathon form-filling sessions need fuel. Create a desktop kit with snacks that won't make a mess of important documents. Dried fruit, nuts, cereal bars, and individually wrapped biscuits can keep you going through the longest paperwork sessions.

Quick Assembly Tips:

- Buy in bulk and split into smaller portions
- Use sealed containers to keep everything fresh
- Rotate supplies every few months
- Include both sweet and savoury options
- Consider any dietary requirements

Beyond the basics, think about adding comfort items that bring a smile - your favourite tea bags, small chocolate treats, or those special biscuits you don't share. Remember to adapt these kits to your needs - if you're dairy or gluten-free, or have other dietary requirements, there are plenty of alternatives available.

Check your kits every couple of months and restock as needed. Winter can be long and demanding - having these small sources of sustenance dotted around your usual spaces can help you stay nourished during the challenging days.



Find Out More: ↘

W

The Nurturing Advocacy Programme



THE Nurturing ADVOCACY PROGRAMME



THE Nurturing ADVOCACY PROGRAMME



- ☆ Disability Rights
- ☆ The Advocacy Basics
- ☆ Nurturing Understanding
- ☆ Nurturing Acceptance
- ☆ Nurturing Advocacy Plan (NAP)
- ☆ Reasonable Adjustment Journey
- ☆ Unreasonable, Reasonable Adjustments
- ☆ 'But No One Believes Me' & 'What Next?'
- ☆ Transitions
- ☆ Imposter Syndrome
- ☆ Supporting Anxiety
- ☆ Calm, Connection & Co-Regulation
- ☆ Introduction to 'The Spoon Theory'
- ☆ Jodie's Top Tips
- ☆ 'How can I Help?'
- ☆ Advocacy Planners Support
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Now on Amazon



Black RAINBOW

“Filled with warmth and humour, and frequently emotional and eye-opening, *Black Rainbow* is ultimately an uplifting story of redemption, self-discovery, finding personal freedom and discovering your own truth.”

Rebecca Huseyin
A Boy Less Ordinary



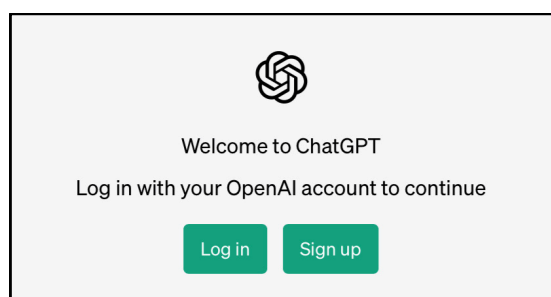
www.pdaparenting.com

ChatGPT- the holiday helper

As we approach the festive season and year's end, parent carers face unique challenges managing holiday excitement, routine changes, and family gatherings. ChatGPT can be your digital assistant during this busy time, helping you plan ahead and maintain calm during the celebrations and transitions ahead.

Finding ChatGPT:

Online Access: ChatGPT is primarily accessible online. You can use it through a **website** or there is also a free App. Once you access ChatGPT, you'll find a simple chat interface, similar to a messaging app.



This column is about empowering you to harness technology for the betterment of your family's life. Each piece of advice, every suggestion, and all creative ideas are shared with the intention of supporting your incredible role as a parent carer.

A few prompts to try

We asked ChatGPT to provide us with some prompts parent carers could use to help them throughout the holiday season.

The joy of ChatGPT is once you get your first response, you can ask it to change things to suit you. You can do this numerous times until you are satisfied with the result.

Holiday Planning and Preparation

Managing Seasonal Changes

Prompt Example: "Help me create a visual countdown calendar for my child who struggles with anticipating holiday changes."

- Tip: Get customisable ideas for making the countdown meaningful and calm, with suggestions for managing excitement levels.

Prompt Example: "I need strategies to help my child cope with Christmas lights and sounds at shopping centres."

- Tip: Receive practical advice for managing sensory challenges during the festive season.

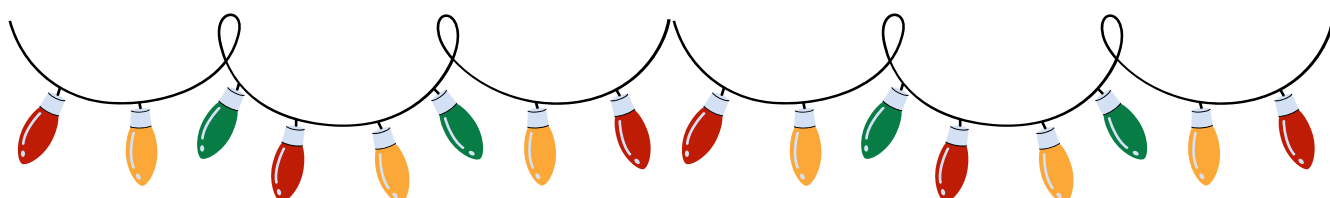
Family Gatherings and Social Events

Prompt Example: "How can I prepare my relatives for my child's needs before our family gathering?"

- Tip: Get help drafting clear, kind messages to family members about accommodations and understanding.

Prompt Example: "Create a social story about visiting relatives during the holidays."

- Tip: Receive customisable stories that can help prepare your child for upcoming social events.



ChatGPT - holidays



Maintaining Routines

Prompt Example: "Help me plan a flexible holiday schedule that keeps some routine while allowing for festivities."

- Tip: Get structured yet adaptable schedules that balance consistency with holiday activities.

Prompt Example: "What are some calm-down activities we can use during busy holiday events?"

- Tip: Receive suggestions for quiet activities and coping strategies during overwhelming moments.

Gift and Activity Planning

Prompt Example: "Suggest sensory-friendly gift ideas for my child who loves music but is sensitive to loud sounds."

- Tip: Get personalised gift suggestions that consider your child's interests and needs.

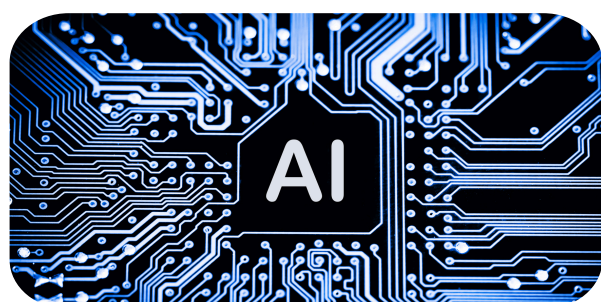
Prompt Example: "Help me plan inclusive holiday activities that all family members can enjoy together."

- Tip: Receive ideas for activities that can be adapted for different abilities and preferences.

Self-Care During the Season

Prompt Example: "I need quick stress-relief strategies for managing holiday preparations."

- Tip: Get practical self-care ideas that fit into busy schedules.



Prompt Example: "Help me create boundaries around holiday commitments while keeping family relationships positive."

- Tip: Receive guidance on politely declining events and managing expectations.

Planning for the New Year

Prompt Example: "Help me create a transition plan for returning to routine after the holidays."

- Tip: Get structured approaches to ease back into regular schedules.



Prompt Example: "What are some gentle ways to help my child understand and cope with the end of the holiday season?"

- Tip: Receive strategies for managing post-holiday emotions and transitions.

Remember, ChatGPT can help you modify and personalise any of these suggestions to better suit your family's specific needs and circumstances. Don't hesitate to ask for clarification or request adjustments to make the advice more relevant to your situation.

The holiday season brings both joy and challenges for parent carers. With ChatGPT as your planning partner, you can prepare for and navigate this time with more confidence and less stress, keeping your family's wellbeing at the center of all celebrations.



The Art of Saying No: Or how to stop being everyone's go to person



Picture this: You're sitting in your car outside school (probably wearing yesterday's jumper and hoping nobody notices), scrolling through approximately 47 unread emails on your phone. There's one from the SENCO asking if you can "pop in for a quick chat" (we all know there's no such thing), three from the class reps about upcoming events that "won't take much organising", and a reminder about that support group you accidentally agreed to help coordinate.

Meanwhile, your phone calendar is pinging with medical appointment reminders, your notebook is bursting with referral forms that needed signing last week, and you're pretty sure you've forgotten someone's medication review.

Oh, and you haven't had a proper cup of tea since 2019.

Sound familiar?



The Professional Yes Person

Let me tell you about the time I said yes to coordinating the summer fair tombola while simultaneously managing three therapy appointments, an EHCP annual review, and what felt like seventeen million pieces of evidence that all needed organising "urgently." Oh, and did I mention this was the same week I'd promised to host the coffee morning for some new parents?

Spoiler alert: The tombola prizes were still in shopping bags by the day of the fair, I turned up to one therapy appointment on the wrong day (classic), and the coffee morning... well, let's just say M&S finest digestives and some slightly squashed fairy cakes from the reduced section count as hosting, right?

The Reality Check

Here's what they don't mention in all those parent carer workshops: **"No" is actually a complete sentence.** You don't need to attach a medical history, three professional reports, and a detailed explanation of your family's weekly schedule to make it valid.

Some tried and tested responses:

"That won't work for us"

- (Notice the 'us' makes it sound like you've consulted a committee)
- "I don't have the capacity right now"
 - (Because 'capacity' sounds better than 'I'm surviving on cold tea and digestives')

"My schedule is already full"

- (Even if that schedule involves hiding in the loo reading chocolate bar wrappers)

"I need to focus on current commitments"

- (Like finding that appointment letter that was definitely on the kitchen table yesterday)

Saying No



The Guilt Factor

Let's talk about guilt. That helpful little voice in your head that says "but they really need someone to run the cake stall" while you're simultaneously trying to remember if you've filled in the DLA form, chased up that occupational therapy referral, and remembered to tell school about next week's hospital appointment.

Here's a revolutionary thought: **Your no is protecting your yes.**

Every time you say yes to organising another fundraiser, you're saying no to something else. Usually, that 'something else' is your own wellbeing or family time. And let's be honest family time might involve breaking up three fights and negotiating with a teenager about why we can't have crisps for breakfast, but it's still important.

The Emergency Kit

For those moments when you're caught off-guard and about to say yes because you're too knackered to think of a no:

1. The "Let me check my diary" response (Buy yourself time even if your diary is actually just covered in appointment letters and coffee stains)
2. The "I'll need to think about that" reply (Works like a charm especially if you follow it up with strategic avoidance)
3. The "I'm not taking on any new commitments right now" answer (Because sometimes honesty is actually the easiest policy)
4. The "I'm waiting to hear back about some appointments" response (Always true we're perpetually waiting to hear back about something)



The Plot Twist

Here's the real secret: **The world doesn't end when you say no.** I know, I was shocked too. The school fête still happens, the coffee morning still runs, and somehow the world continues turning even if you don't volunteer for every committee going.

And yes, some people might not like your no. They might try to convince you, guilt you, or remind you of that one time three years ago when they covered the school run for you. Stand firm, warrior. Your energy is precious, and you don't need to set yourself on fire to keep everyone else warm.

Remember: You're not saying no because you're mean or unhelpful. You're saying no because you're human, with limited energy and time, and you're smart enough to know that sometimes the most responsible thing you can do is absolutely nothing.

And if all else fails, remember this: Cake tastes better when you're not exhausted from saying yes to everything.



About KinToa

Welcome to **KinToa**, your beacon in the journey of SEND parent caregiving. At KinToa, we see the real heroes: you, the parent carers, who navigate the complexities of special educational needs and disabilities with unmatched strength and courage.

Our Philosophy: KinToa, merging 'Kin' and the Maori word 'Toa' for warrior, stands as a symbol of your inherent bravery and resilience. It's more than our name—it's our commitment to honour your journey.

Understanding Your Challenges: Forget the superficial fixes like another hand massage at carers' meetings. You deserve practical, real-world support tailored to the unique demands of your life. KinToa is designed to be that robust pillar of strength, offering hands-on advice, relatable stories, and a sense of solidarity that cuts through the isolation often felt in the world of SEND caregiving.

Why KinToa? Because true strength lies in unity and shared wisdom. Our content is curated to resonate with your experiences, enlighten your caregiving path, and inject moments of joy and discovery into your daily routine. From navigating SEND systems to celebrating personal victories, we cover the spectrum, ensuring you feel seen, understood, and most importantly, not alone.



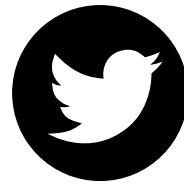
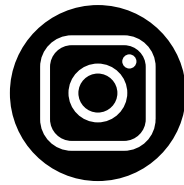
Our Mission: To empower you, the hero, in your quest. KinToa stands as your guide, illuminating the path with insights, empathy, and encouragement. We're more than a magazine; we're a companion and a champion for the incredible work you do every day.

Join Our Family: Dive into a world where empathy meets action, where your stories and challenges light the way for others. With KinToa, embark on a journey of empowerment and connection, knowing that, together, we're invincible.

Thanks to **Jodie** from
The Nurture
Programme for her
amazing design work



Because nothing is typical!



*Debs
Aspland*

EDITOR IN CHIEF

Debs is a mum to three amazing, challenging, loveable teenagers, each with a variety of special educational needs and disability labels attached.

Over the years, Debs has spent hours trying to juggle the chaos that comes from having to use a system that doesn't actually work, unless you shout loudly and constantly. Even then, there are no guarantees.

She has turned up late for meetings, a month early for some and even, on one occasion, to the wrong building.

She has set up support groups, forums, online support, accessible music festivals, award events and much more.

Her biggest passion?

Making life that bit easier for other parent carers.

Oh, and stationery. She has a real passion for stationery (and cake)! She really loves cake.

Her biggest fear?

One day, her husband will find out that some other partners enjoy cleaning and doing housework.

The Dream?

KinToa envisions a world where every SEND parent carer feels empowered, connected, and fully supported in their pivotal role

This will give them more time to do the things they want to do, rather than just doing the things they need to do. And if that involves cake, they know who to call.

KINTOA

Strength of Family, Courage of Warriors

January/February 2025

